



## Symptoms of depression, anxiety, and stress in parents of young children with epilepsy: A case controlled population-based study

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### ABSTRACT

The objective was to provide population-based data on depression, anxiety, and stress in parents of young children with epilepsy and to compare findings with those of parents of developmental-, age-, and gender-matched children with nonepilepsy-related neurodisability (neurological and/or neurodevelopmental concerns). The parents (mothers and fathers) of 47 (89% ascertainment) young children (1–7 years) with epilepsy in a defined geographical area of the UK completed the Depression Anxiety Stress Scales – Short Form (DASS-21), a screening measure for depression, anxiety, and stress. The responses of parents of children with epilepsy were compared with parents of developmental-, age-, and gender-matched children with nonepilepsy-related neurodisability ( $n = 48$ ). Factors associated with parental symptoms were analyzed using regression. In the group with epilepsy, 47 mothers and 39 fathers completed the DASS-21. Seventy-two percent of mothers scored in the at-risk range on at least one DASS-21 subscale (Fathers 49%). Mothers of children with epilepsy were significantly more likely to score in the at risk range than fathers on depression (55% vs. 33%), anxiety (47% vs. 26%), and stress (55% vs. 31%) subscales (all  $p < 0.05$ ). Mothers of children with epilepsy were also significantly more likely to score in the at-risk range than mothers of children with neurodisability on measures of depression ( $p = 0.005$ ) and stress ( $p = 0.03$ ). There was not a significant difference between fathers in both groups on any measures. In the group with epilepsy, increased child emotional-behavioral difficulties were associated with increased DASS-21 scores on multivariable analysis ( $p = 0.04$ ). Mothers of young children with epilepsy are at high risk for mental health difficulties, and all should be screened for such difficulties. There is a need to explore what parent and/or child focused interventions might be useful to reduce the mental health difficulties reported by mothers of young children with epilepsy.

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### 1. Introduction

Childhood onset epilepsy can have a very significant impact on family functioning with high rates of maternal anxiety and depression being reported [1,2]. Additionally, families of a child with epilepsy have been found to experience significantly more stress and restrictions in family life than other families [3,4]. As well as impacting on the parents themselves, parental mental health symptoms can impact negatively on behavior in children with epilepsy [5] underlining the need to identify and provide support for these problems.

In addition to epileptic seizures, epilepsy in childhood has a high association with neurobehavioral difficulties [6]. These neurobehavioral difficulties often have a significant impact on health-related quality of life [7,8]. Early onset epilepsy, in particular, is often associated with a combination of difficult to treat seizures and a high frequency of developmental and epileptic encephalopathies [9,10].

There is a lack of population-based data on mental health functioning in mothers of children with epilepsy and limited data of any sort among fathers. There is also a lack of studies which have compared parents of children with epilepsy with parents of children with other neurological or neurodevelopmental problems. The aim of the Sussex Early Epilepsy and Neurobehavior (SEEN) study was to provide population-based data on the prevalence of significant symptoms of depression, anxiety, and stress in parents (fathers and mothers) of young children with

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epilepsy. A secondary aim was to compare findings with those of parents of developmental status-, age-, and gender-matched children with nonepilepsy-related neurodisability (neurodevelopmental and/or neurological difficulties). A final aim was to provide data on factors (child epilepsy, child neurobehavior, and parental socioeconomic) associated with mental health symptoms in parents of young children with epilepsy.

## 2. Materials and methods

### 2.1. Recruitment in the SEEN study

All children born between 2008 and 2014 with epilepsy (a history of two or more unprovoked seizures more than 24 h apart) and who were residents in the RH10 to RH14 postal districts in the south of the United Kingdom between September 30th 2014 and February 29th 2016, were eligible for inclusion. Additionally, children needed to be at least 1 year of age during the study period in order to be included. The prevalence of lifetime epilepsy (a history of 2 or more unprovoked epileptic seizures) in the study area was calculated by using the 2011 UK census population data of 1 to 7-year-olds (19,393) provided by the Office of National Statistics (2011 UK census total population 217,006). With respect to ethnic make-up, the area is similar to the UK average (study area: White: 87%, non-White: 13%, United Kingdom: White: 88%, non-White: 12%; Office of National Statistics, UK).

Eligible children with epilepsy were identified via a link pediatrician on the research team. All pediatricians, neurophysiologists, and epilepsy nurses in the study area were asked to inform the link pediatrician of current and new diagnoses of epilepsy within the study period. The parents/guardians of eligible children were approached by the researchers (sent a letter and/or asked in person) and asked to complete an interest form if they wished to find out about the study. All parents who returned a form were met in their home by one of the study psychologists. At this informed consent meeting, the study was described in detail and parents were asked for written consent for entry of their child and themselves into the study.

Once a child with epilepsy was enrolled in the study, the parents of children with similar attributes (age, gender, and estimated developmental level) without epilepsy attending the same clinics in the study area were approached by collaborating pediatricians. The children needed to have been referred for a neurological or neurodevelopmental concern. Developmental level was estimated based on school/preschool placement (special or mainstream), previous psychological/developmental assessment, or clinician judgment. The parents of children with nonepilepsy-related neurodisability were then approached in the same manner as parents of children with epilepsy.

### 2.2. Child and parent assessment

Eligible children in both groups underwent comprehensive psychological assessment in their homes, including measures of global development, sleep, and emotional-behavioral functioning between November 1st 2014 and April 30th 2016. Global development was assessed using the Griffiths Mental Development Scales (GMDS) [11] or the Griffiths Mental Development Scales-Extended Revised [12] which yields an overall Developmental Quotient (DQ). Child sleep was measured using the Child Sleep Habits Questionnaire (CSHQ) [13,14]. Child emotional-behavioral functioning was measured using the Strengths and Difficulties Questionnaire (SDQ) [15]. The SDQ is a screening instrument for behavioral/psychiatric difficulties [15] and can be used with parents of children 2 years and older. The SDQ was not used with children younger than 2 years of age or with a developmental level deemed inappropriate for assessment (excluded children: 26; epilepsy:  $n = 10$ ; neurodisability:  $n = 16$ ).

Clinical information on all children was extracted (using a standardized proforma including data on current Anti-Epileptic Drugs (AEDs), seizures, and investigations (Magnetic Resonance Imaging (MRI) Electroencephalography (EEG)). Clinical, EEG, and neuroimaging data for the children with epilepsy were reviewed by 2 pediatric neurologists who manage patients with epilepsy in their clinical practice. They independently classified seizures (as primarily generalized or focal), and epilepsy syndromes/epilepsies and etiology/cause proposed by the Task force of the International League Against Epilepsy (ILAE) in 2010 [16]. When the assessors disagreed on the classification, conflicts were resolved by a third rater.

### 2.3. Parent assessment using the Depression Anxiety and Stress Scale – Short Form (DASS-21)

The DASS-21 was part of a parental research pack given to the parent self-identified as the primary caregiver at the time of child assessment. This parent was instructed to give the corresponding parent the relevant survey. The surveys were collected by the research team in the parents' homes at a subsequent visit. Both fathers and mothers of participating children were encouraged to complete the DASS-21.

The DASS-21 is a 21-item self-report measure of depression, anxiety, and stress. It is a short version of the full 42-item DASS [17]. The DASS-21 has been found to be a valid measure of depression, anxiety, and stress [18]. It has good psychometric properties [19] and is a valid measure across racial groups [20]. Each subscale has 7 items based on 4-point Likert scale (0–3 scale) (Never, Sometimes, Often, Almost, Always). It has good psychometric properties. Scores in the abnormal/at-risk range are Depression (>4), Anxiety (>3), and Stress (>7). Normative data from a large UK-based clinical sample showed that scores above the Depression cut-off were equivalent to the 81st percentile or higher, scores above the Anxiety cut-off were equivalent to the 86th percentile or higher, and scores above the Stress cut-off were equivalent to the 82nd percentile or higher [18].

Parents also provided information on their highest level of education (categorized as attending full-time education to 16 years (formal education) or fulltime education beyond 16 years (beyond formal education)) total amount of hours worked per week, age in years, and employment (in paid employment/not in paid employment). Parents also provided information regarding whether they had been previously professionally diagnosed with epilepsy or a mental health condition.

Deprivation status was determined by the Index of Multiple Deprivation (IMD) 2015 rankings (Department of Communities and Local Government, *English indices of deprivation*. Retrieved from <http://imd-by-postcode.opendatacommunities.org/> (Accessed December 15th 2016)). Lower scores are associated with lower deprivation. Home postcodes were used to establish the IMD 2010 ranking of each family.

### 2.4. Statistical analysis

Descriptive statistics were used to characterize scores on the DASS-21.

#### 2.4.1. Between-group analysis

*t*-Tests or chi-square analysis/Fishers exact test was used to compare the group with epilepsy and the group with neurodisability with respect to parental age, education level, deprivation, employment status, hours worked, previous diagnosis of mental health problems, and children with respect to age, DQ, sleep, and SDQ scores.

Chi-square analyses were used to compare the proportions of mothers/fathers in the at-risk range in the group with epilepsy compared with the group with neurodisability on the DASS-21. Mean symptom scores on the DASS-21 for mothers/fathers in the group with epilepsy were compared with mothers/fathers in the group with neurodisability using independent samples *t*-tests.

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